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REPORT OF THE PANEL ON VISUAL IMPAIRMENT AND ITS REHABILITATION

Volume Two/Part Six



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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES Public Health Service National Institutes of Health

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PREFACE

THIS IS THE Report of the Panel on Visual Impairment and Its Rehabilitation, which is Part Six of Volume Two, Reports of the Program Panels, of the multivolume report of the National Advisory Eye Council entitled, Vision Research—A National Plan: 1983-1987.

The complete National Plan presents a comprehensive and detailed assessment of the current NEI program as well as specific recommendations for program development over the next five years. These include program priorities and projections of resource requirements for each major area of vision research that the NEI supports. Readers desiring additional information should consult the following volumes:

Executive Summary (Overview of the entire Plan).

Volume One—The 1983 Report of the National Advisory Eye Council (Background, Summary Panel Reports and Resource Requirements, Implementation Strategy, Cross-Cutting Research Areas and Issues, Planning Participants, Planning Strategy and Process).

Volume Two—Reports of the Program Panels

Part One—Report of the Retinal and Choroidal Diseases Panel

Part Two—Report of the Corneal Diseases Panel

Part Three—Report of the Cataract Panel

Part Four-Report of the Glaucoma Panel

Part Five—Report of the Strabismus, Amblyopia, and Visual Processing Panel

Part Six—Report of the Panel on Visual Impairment and Its Rehabilitation.

Volume Three—Support for Vision Research (Data on vision research projects supported by the NEI in FY 1981 and by other government and private organizations in FY 1980):

The NEI programs addressed in Parts One through Five of this volume each encompass research on diseases and disorders that can produce blindness as well as lesser degrees of visual impairment which also are disabling. Some people with impaired vision can get along quite well with simple optical and mechanical aids. Others require more specialized and sophisticated devices. Only in recent years has the extraordinary diversity of visual characteristics and rehabilitative needs within this group of people begun to be appreciated.

Although the NEI has no separate program for research in this field, the necessity to address these needs is an integral part of the goals and objectives of each of the five disease-oriented programs. Thus, projects in visual impairment and its rehabilitation are funded out of the NEI program to which they most closely relate. Projects that do not focus on a specific disease are generally funded within the Strabismus, Amblyopia, and Visual Processing program. Because of increasing awareness of and interest in the problem of visual impairment and its rehabilitation among professionals and the public alike, the Council established a special program planning Panel to consider research needs, opportunities, and priorities in this field. This includes research aimed at enhancing the remaining vision of individuals, evaluating new and existing optical aids, studying video magnification or image enhancement systems, and other techniques and strategies aimed at improving visual capabilities and performance.

VISUAL IMPAIRMENT AND ITS REHABILITA-TION

INTRODUCTION

STUDIES OF VISUAL IMPAIRMENT and its rehabilitation have not flourished as has biomedical vision research in general, and the needs of visually impaired persons have not been addressed in a comprehensive fashion. Increased research and direct service through a variety of mechanisms are required if visually impaired people are to function optimally in today's world. Meeting the needs of these people will require a multifaceted effort aimed at maximizing the effectiveness of programs concerned with visual impairment and its rehabilitation. This will involve additional research projects, the development of broadly based research and training programs in a wide range of clinical and academic settings, and improved communication among governmental agencies, including the National Eye Institute, relevant private organizations, and visually impaired individuals.

A significant number of Americans have irreversibly impaired vision. Although some are totally blind, more than 90 percent retain a degree of usable residual vision. ¹ These people are said to have "low vision" or "partial sightedness." It should be noted that the term "legal blindness" includes both the totally blind and those with the more disabling levels of low vision.

Within the visually impaired population, there is a wide diversity of visual characteristics and rehabilitative needs: loss of visual acuity may range from slight to profound; visual field loss may be predominantly peripheral or predominantly central, with severity ranging from slight to profound; or other vision problems may exist, such as night blindness, color blindness, decreased contrast sensitivity, sensitivity to glare, or prolonged recovery from the effects of glare. The extent of the handicap created by the visual impairment depends not only on the nature and extent of the visual loss, but also the needs, aspirations, attitudes, and physical abilities of the affected individual. Some of the more handicapping disabilities resulting from impaired vision include diminished ability to read, recognize faces and facial expressions, perform visually guided motor tasks, or be aware of the important features of one's immediate environment.

Although there is no generally accepted single definition of low vision that encompasses all individuals with subnormal visual acuity or abnormal visual fields, uncorrectable central vision of 20/70 or less is the visual acuity criterion most commonly used. ²

Some data on the prevalence, incidence, and causes of visual loss have been obtained through population censuses, estimates from past data, projections from small samples to larger populations, or through registers or surveys. Each of these methods has certain deficiencies; ³ as a consequence, available figures on the incidence and prevalence of visual impairment in our society are only approximate.

In 1980, the National Society to Prevent Blindness (NSPB) ¹ estimated that there were 11.4 million people with impaired vision in the United States; of these, 1.4 million had severe visual impairment and about 500,000 of these were legally blind (best corrected central visual acuity equal to or less than 20/200 in the better eye, or a field of vision no greater than 20 degrees in its widest diameter). This report estimated that 21 new cases of legal blindness occur each year per 100,000 people, or a total of 46,600 new cases of legal blindness annually. The

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overall prevalence rate for legal blindness in the United States is estimated to be 228.4 per 100,000 people; this rate varies widely, from 139 per 100,000 in Hawaii to 370 per 100,000 in the District of Columbia.

A comparison of American and British statistics on legal blindness illustrates the difficulties in collecting reliable figures, particularly for subpopulations. In American school-aged children in 1970, the incidence rate was 5.1 per 100,000. For British schoolchildren in the same period, the rate was 1.35 per 100,000. For persons over 85, the incidence rates were 203 per 100,000 in the United States and 745 per 100,000 in Britain. The reasons for these differences are unclear; they may reflect differences in standards for legal blindness or sociological factors affecting the registration of legal blindness in the two countries.

Figures for 1969–1970 from the Model Reporting Area for Blindness Statistics (MRA)⁵ indicated that 67 percent of the legally blind persons in the United States were over age 50, 52 percent were over 60, 37 percent were over 70, and 20 percent were over 80. Clearly, these data demonstrate that severe visual impairment is predominantly associated with the older adult population. Because the average age of the population is increasing rapidly, visual impairment among older Americans is becoming a problem of even greater significance.

Among the younger population, boys are more likely to be visually impaired than girls, perhaps because they are more likely to have certain congenital disorders and are more likely to sustain ocular trauma. ⁵ Among older people, there are more visually impaired women than men, due mainly to the longer life span for women. The incidence of legal blindness is substantially higher in the nonwhite population; this is due partly to a higher incidence of glaucoma and corneal disorders, ⁵ partly to a lower quality of care available to these people, and partly to poorer patient compliance with prescribed treatment.

The MRA studies indicated that the principal causes for new additions to state registers of the legally blind in 1970 were retinal degeneration (18.2 percent), other retinal conditions (15 percent), cataract (12.8 percent), and glaucoma (11 percent). Frequently, visual loss has multiple causes; for example, cataract and retinal complications are both common in diabetes. This can confound the classifying and the monitoring of visual loss.

Although these data give some idea of the incidence, prevalence, and most frequent causes of visual impairment, it must be recognized that significant problems are associated with establishing a data base for epidemiologic analysis. One difficulty is a reluctance among people to be identified as visually handicapped or classified as legally blind for fear of losing their jobs or drivers' licenses. On

the other hand, others are reluctant to undergo further evaluation of their vision for fear that they might become ineligible for benefits they already receive. Another difficulty is the fact that different standards of vision are used to determine eligibility for certain benefits, privileges, licenses, jobs, and compensation for injury.

The principal criteria for establishing visual impairment are usually visual acuity scores, but other standards also need to be considered. However, there clearly are difficulties in developing any quantitative index of visual loss, even if field measurements or tests of other functions such as dark adaptation, color vision, contrast sensitivity, or other critical parameters are considered along with visual acuity scores. 6 In large measure, the significance of the deficit relates to the task the individual wishes to perform, and his or her aspirations, attitudes, and physical abilities. It has been suggested that visual loss should be assessed by the magnitude of the handicap created or the disability exhibited at common tasks, rather than on clinical tests of visual function. 7 Criteria for the draftsman, truck driver, and farmer can be quite different.

As a result of new medical and surgical treatment methods, many persons who would have become essentially blind in years past now are able to retain some vision. 8 However, for most visually impaired individuals there is no prospect of curative treatment. Thus, partially sighted and totally blind people must be helped to make the best use of their remaining abilities so that they can perform tasks that are important in the workplace or daily living. This may require supplementing visual capacity by magnifiers or other optical devices, by video magnification or image enhancement systems, or controlling the luminous environment. It may also involve training in techniques for altering the use of peripheral vision or other strategies aimed at improving the performance of visual tasks. Techniques or devices that partially or completely substitute for vision may sometimes be needed, such as the use of braille, canes and guide dogs, reading machines, talking books, and specialized aids for manual activities such as needle threading devices.

The broad sociological impacts of visual impairment are often overlooked. These include the economic effects of losing trained people from the workforce because of visual impairment, as well as the costs of rehabilitation, retraining, and providing special equipment. Also, there are personal considerations; adjustments often need to be made within families, workplaces, schools, and in other community and social situations for an individual with impaired vision.

When considering the impact on and the needs of the visually impaired, special attention should be given to the young. This includes assessment of the enormous costs to both the individual and society for medical treatment, rehabilitation, special education, and a lifelong need for special services, often in the face of limited income. An added problem is the reduction of human potential among the individuals affected.

Many impairments of vision that occur early in life are accompanied by other handicaps and sensory deficits. Common examples are the simultaneous deficits of vision and audition which occur in Usher's syndrome (retinitis pigmentosa and hearing loss) and in maternal rubella (German measles). The education, training, and care of individuals with multiple handicaps present especially difficult problems to educators, therapists, families, and society.

RESEARCH GOALS

- To advance research designed to enhance the rehabilitation, training, and quality of life of blind and partially sighted persons.
- To develop methods for specifying and measuring loss of visual function that will improve the characterization and categorization of visual handicaps.
- To develop improved epidemiologic data for blindness, partial loss of sight, and visual anomalies that will enhance the development of research, training, and service planning functions for these populations.

OVERVIEW OF CURRENT RESEARCH SUPPORT

In June 1977, a workshop on "Research Opportunities Relevant to the Management of Severe Visual Impairment," organized by the National Advisory Eye Council, emphasized the inadequacy of the research effort in this field. As a result, the National Advisory Eye Council declared this an area of high program relevance and the NEI staff issued a Program Announcement requesting grant applications for research on "methods and approaches for the prevention, evaluation, and management of severe visual impairment." (NIH Guide for Grants and Contracts 7, No. 15, Oct. 16, 1978, pp. 1–3).

At present, the National Eye Institute is the leading source of support for low vision research; 23 projects with some direct relevance to low vision were supported in FY 1981, at a total cost of \$1.7 million. Of these, only two grants, totalling \$34,000, were concerned primarily with low vision; the others were designed to characterize visual function

in a variety of disorders. Two other grants supported by the National Eye Institute, totalling \$132,000, were directed toward research on the rehabilitation of blind persons.

As part of its program to develop research capabilities in institutions where there is little funded research activity, the Division of Research Resources of the National Institutes of Health has awarded grants to the New York Association for the Blind in New York City and the Pennsylvania College of Optometry in Philadelphia for the initiation of research on low vision. Limited funding for low vision research is also provided by the National Institute on Aging and the National Institute of Child Health and Human Development, both of the National Institutes of Health; by other organizations within the Department of Health and Human Services such as the National Center for Health Services Research; by organizations within the Department of Education such as the National Institute of Handicapped Research, Office of Special Education, and Bureau for the Blind and Visually Handicapped; the Veterans Administration; Department of Defense: and the National Science Foundation. It is crucial that national efforts in behalf of the visually impaired population be coordinated for more effective programmatic development.

RECENT ACCOMPLISHMENTS

Although only a limited amount of research on visual impairment has been conducted, the eye care professions have given substantially increased emphasis to low vision and its correction over the past decade. The textbooks of Faye, 9-11 Mehr and Fried, 12 Sloan, 13 Fonda, 14 and Bier 15 have been strong influences.

Methods of Evaluating Visual Performance

There are two major problems in assessing visual function. First, the quality of visual function must be determined in an unambiguous manner and the response characterized quantitatively as normal or abnormal. Second, it is necessary to determine which visual functions are impaired in different types of disorders so that the information can be used as a guide to appropriate diagnosis and therapy.

Although clinical measurement of visual acuity is considered an elementary (and common) procedure, it is becoming recognized that test chart design can substantially influence visual acuity scores and that this is especially true for persons with low vision. Recently, a working group of the National Academy of Sciences/National Research Council Committee on Vision recommended standard procedures for the measurement and specification of visual acuity, ¹⁶ and new charts have been designed by Bailey and Lovie ¹⁷ and by Sloan ^{18,19} with a view to improving the reliability of visual acuity measurements.

The assessment of performance when reading continuous text is considered to be important in most low vision clinical examinations, and Keeler 20 and Sloan 21 have developed chart designs that use passages of high contrast continuous text as the test material. Bailey and Lovie 22 have developed a reading chart that contains somewhat standardized rows of unrelated words that follow a systematic size progression over a wider range of sizes. This chart design eliminates context as a contributor to reading efficiency, and it may provide a better evaluation of visual efficiency for reading and reading acuity.

Quillman, Mehr, and Goodrich ²³ have used a modified Frostig figure-ground test to evaluate integrative and differentiative abilities of central vision. This group ²⁴ also has helped to develop techniques to evaluate and train people in extrafoveal viewing, and they have advocated assessment of the ability to sustain reading activity as a criterion in the evaluation of visual performance.

Contrast sensitivity function (CSF) 25-37 measurements have been used increasingly in the evaluation of visual function in patients who are experiencing visual loss. CSF measurements examine the just detectable contrast for different sine or square wave frequencies. The assumption underlying this analysis is that seeing any object represents some combination or synthesis of frequencies. High-frequency determinations correspond to some degree with other measurements of visual acuity. In specific pathologies, certain line or grating frequencies are affected more or less than others. One problem in the application of these measurements is that standardized tests have not yet evolved and the literature is somewhat confusing because light level, refraction, pupil size, glare, and test distance all affect the result. A second problem in interpreting the results is that testing at some of the coarser frequencies requires large targets, so that it is not clear what portion of the retina is being used to respond to these tests and whether the same area is used at different frequencies.

Qualitative differences between the visual processing of low and high spatial frequency stimuli, the sustained/transient dichotomy, and differences in frequency selectivity may be significantly modified in low vision. Thus, the standard procedures for measuring contrast sensitivity may not accurately describe the vision of persons with marked visual

field defects. These differences in visual processing could have functional consequences and their measurement could provide insight into underlying pathology. Other difficulties in estimating or assessing the quality of retinal function are caused by the presence of relatively dense opacities of the visual media. The latter topic is generating active research interest. ³⁸ Techniques such as interference acuity measures, visually evoked responses (VER) to laser speckle and through the lid VER, and hyperacuity test designs are being used to assess the problem.

Visual loss need not be limited to central fine vision but can reflect changes in response in different parts of the visual field. In fact, loss of peripheral vision often causes a more severe handicap than loss of central vision. Retinitis pigmentosa, gyrate atrophy of the retina, choroideremia, and glaucoma may cause loss of peripheral vision. In some disorders, such as multiple sclerosis or optic neuritis, loss of sensitivity is greatest at high light levels. 39 Glare effects from cataracts and scattering elements in any of the ocular media can be devastating in a brightly lit environment but much less debilitating at low luminance levels. In certain retinal diseases, recovery from the effects of bright light is slowed greatly, whereas anomalies affecting the anterior segment of the eye often produce great discomfort in bright light. Night blindness and marked color vision disorders occur in other pathological processes, and severe color vision disorders can greatly handicap an individual.

Sophisticated test procedures are often needed to classify properly the visual anomaly and locate the site and extent of the lesion. 40 By improved classification and localization of specific lesions, it should be possible to improve their remediation. Berson and Ripps and their co-workers have concentrated on the outer retinal response and adaptive mechanisms. 41 Enoch has sought to develop a layer-bylayer perimetric analysis of visual response. 40 Adams has studied color anomalies in a number of retinal diseases. 41 Regan has concentrated on anomalies of conduction in the visual pathways central to the retina per se. 41 The research projects mentioned above are discussed in greater detail and additional references provided in Volume Two, Part One, Report of the Retinal and Choroidal Diseases Panel, Chapter 13, "Noninvasive Techniques in the Study of Retinal Disorders."

In addition to visual acuity and field measurements, contrast sensitivity evaluation and other modern techniques can be used to help identify the visual abilities of people with low vision and enable them to make the best use of their residual function. It should be possible to compensate partially for visual loss by combining specific image processing adjustments, such as border enhancement of a display, brightness, and specific frequency contrast

enhancement, with magnification of the image and control of the patient's immediate environment.

Devices Useful to the Visually Impaired Population

Some important new aids for blind and visually impaired persons have been developed recently. New spectacle-mounted bioptic telescopes of Keplerian design and several different hand-held monocular telescopes with wide ranges of focus are now available. 42,43 There have been some attempts 44,45 to improve reversed telescopes, which can increase the amount of information perceived by people with severely limited visual fields. In addition, Fresnel prisms strategically placed on selected portions of spectacle lenses are being used to assist persons with peripheral field loss. 46 Wider fields of clear vision can be obtained through the use of aspheric lenses and spaced lens systems with newly improved microscopic (high positively powered) lenses.

Bailey ^{47,48} recently has developed new methods for measuring the key optical features of optical aids for low vision. Another advance in optics has been the development of glass with a high refractive index which does not cause the same chromatic problems associated with heavier lead flint glass; this is important in lenses of high power. Tinted lenses also have received attention, and new high-density tints with low infrared transmission are becoming available. Tinted lenses with different selected spectral transmission characteristics are being tested on persons with retinitis pigmentosa.

Further innovations and improvements have been made in video magnification systems; ⁴⁹ image quality has improved, more optional features and a wider range of models are available, and a variety of split-screen capabilities have been devised ^{50,51} to assist in classrooms, typing, and microfiche reading. These instruments may be adjustable with respect to brightness, contrast, and border enhancement characteristics of the image to suit the needs of partially sighted people.

Improved electronic voice synthesis has led to the development of a range of devices such as talking calculators, clocks, scales, thermometers, and calipers. Good progress has been made with reading machines that convert printed material into a synthesized voice output. ⁵²

Several new aids to mobility have been developed to assist the user in detecting obstacles and hazards in his or her path. Some of these devices use radar reflection principles to give auditory or tactile information; the laser cane, the Sonic Guide, and the Mowat sensor are examples of such devices.

Aids are being developed to help with night vision problems of the kind commonly experienced by persons with retinitis pigmentosa. Compact image conversion and intensifier systems, utilizing

infrared viewing technology, can produce a visible image of an otherwise indistinguishable environment. ⁵³ A new light source provides a reasonably intense and wide beam of light that can be very useful to persons with retinitis pigmentosa and other conditions in which there is both field constriction and diminished night vision. ⁵⁴

There have been advances also in devices that utilize the tactile sense in tasks that usually require vision. The Optacon produces a tactile image of printed material so that reading can be accomplished with a finger. Systems have also been developed to translate video camera images to impulses that drive an array of tactile stimulators applied to a skin area. There has been experimentation with retinally or cortically implanted electrodes that create visual sensations when light falls upon directionally sensitive light-sensing systems. A major problem with this approach is designing an electrode that will be accepted by the body for continuous use.

Braille continues to be widely used by blind and profoundly visually handicapped individuals, but some people think that the entire braille concept requires reexamination. It is a valued skill, but it also tends to isolate blind people from the rest of society. Some new developments that may lessen this problem include paper in which a welt is raised after the application of pressure. 55 This allows hand brailling to be done in a positive format rather than the usual negative or reversed manner and makes it possible for either sighted or nonsighted individuals to write messages that can be read by others, sighted or nonsighted. Other advances have been made in the electronic generation, storage, and retrieval of information in braille, using mechanically refreshable braille displays such as cassette braille. Inputs for such systems may be through a braille keyboard or a regular typewriter terminal keyboard.

Identification of Rehabilitation Needs

In general, there has been increasing awareness of the desirability of maximal independence for handicapped persons, and simulated environments have become more widely used in rehabilitative training, especially in daily living skills. The problems of those with reduced vision adapting to the visual environment have been studied through a recent survey of a diverse group of partially sighted individuals. ⁵⁶

Until recently, only limited formal specialized training in low vision has been available to ophthal-mologists, optometrists, and researchers. The eye care professional organizations have established special interest sections in low vision: in 1973, the American Academy of Optometry implemented a

Low Vision Diploma Program (specialist recognition), in 1979 the American Academy of Ophthalmology established a Low Vision Committee, and in 1981 the American Optometric Association created a Section on Low Vision. Still more recently, a few residency programs in low vision have been developed in schools of optometry and at the New York Association for the Blind (The Lighthouse), in New York City. Also, there has been some formal specialized low vision training for ophthalmic assistants and technicians.

In the last decade, the formal training of rehabilitation personnel, such as orientation and mobility instructors and rehabilitation counselors, has grown considerably. The need for specialized counseling services, rehabilitation counselors, special education teachers for the visually handicapped, social workers, and occupational therapists has been recognized. Until now, research and the provision of rehabilitative services have been directed mainly to blind people, but both functionally blind and partially sighted people need to be served.

Although the need for training blind people in a variety of skills has long been recognized, only recently has any emphasis been given to training persons who are partially sighted. Clinical procedures have evolved, sometimes out of formal research and at other times not, to train persons with macular disorders to develop extrafoveal viewing strategies, ²⁴ and to train persons with visual field defects to utilize the partial prisms ²⁵ that may aid visual orientation and navigation, or to use spectacle-mounted bioptic telescopes for enhanced mobility.

RESEARCH NEEDS AND OPPORTUNITIES

This section outlines research needs in the field of visual impairment and its amelioration from a broad perspective that emphasizes the multidisciplinary approach needed to deal effectively with these problems. In addition to research that should be supported by the National Eye Institute, this section also includes discussion of studies that would be most appropriately supported by other Federal agencies, private organizations, or industry.

New diagnostic tests of visual function need to be developed. This will require additional investigation of the visual characteristics, both capacities and incapacities, of individuals with low vision. Many aspects of vision need to be explored, including resolution performance with high contrast targets such as gratings, letters, rows on Snellen charts, and a variety of typeface materials. The effect of contrast and luminance on visual efficiency and

resolution also needs further study. Tests of performance efficiency and motor behavior during visual tasks need to be developed and used in order to understand the characteristics of different types of visual impairment. Responses to defined therapies for the specific problems or visual deficits need to be assessed.

Additional techniques should be developed to evaluate retinal function in the presence of opacities of the ocular media. Such information would aid the ophthalmologist in making decisions about therapy, including surgery, in properly classifying cases for epidemiologic analysis, and in improving prognosis.

Visual impairment needs to be defined more precisely. Standard methods need to be established for recording clinical data from low vision patients and specifying degrees of visual impairment. The development of standard nomenclatures, classifications, and data recording protocols would greatly facilitate the collection and comparison of statistics from various clinics and offices and provide a strong basis for research on client utilization, prescribing patterns, epidemiology of visual impairment, and changing needs of the visually impaired population.

Sufficiently large patient pools must be analyzed to determine accurately the causes, distribution, and characteristics of visual impairment, and the part of the visual field in which the loss is manifest. 40 For certain purposes, age-based evaluations are necessary; for others, the cause of visual loss, such as albinism, senile macular degeneration, or others, is pertinent. For essentially all types of visual impairment, it is important to identify the specific cell type or group that is affected (for example, photoreceptors, ganglion cells, or others). Some of the questions that might be asked are: Is the anomaly in the central retina or peripheral retina? How extensive is it? What functions are altered by specific deficits? Is there more than one ocular problem? Are there multiple sensory deficits? What is the prognosis? What are the effects, actual or probable, of specific therapies, such as panretinal photocoagulation, on visual function? This knowledge could prove useful in understanding the disturbance of visual function and in defining the remedial actions needed in the design of visual aids.

Current epidemiologic data on the visually impaired population, particularly for the partially sighted group, are generally inadequate; most available data relate to legal blindness or total blindness and often do not meet the needs of research or planning groups. Little information is available on multiple ocular problems, multiple handicaps, and the degree of incapacitation. The economic impact on individuals and society resulting from visual losses has hardly been considered.

Research in visual impairment presents a special set of difficulties, which should be recognized and taken into account when grant proposals for such studies are reviewed. The complex nature and the diversity of the manifestations of low vision make experimental design very difficult. Even within defined categories of low vision population groups, there is a great diversity of individual residual vision capacities and adaptations. These heterogeneities often prevent rigorous application of experimental methods, and it may be especially difficult to predict what kind of statistical analysis will be most appropriate or how well each of the subjects will be able to participate in all phases of the experimentation. Thus, suitable experimental and statistical low vision models that could be used for in-depth studies on very small subject populations need to be developed.

The optical and other rehabilitative needs of low vision patients who share common vision characteristics need to be identified. New aids need to be developed, as well as improved methods for evaluating the optical characteristics of aids. Also needed are standards for the nomenclature, specification, and quality of optical aids, better methods to test performance with vision aids, and assessment of the contribution they make to the rehabilitation of persons with low vision. This includes identification of the key optical features of low vision aids and how they should be measured and specified. Clinical trials of optical aids need to include populations large enough to define accurately the best therapeutic strategies.

Access to reliable information on visual aids through catalogs or manufacturers' literature would significantly assist the clinician in making judgments about which aids best suit the needs of the patient. The existence of standards also should influence optical manufacturers, encouraging them to maintain good control of the quality of their products. Results of these studies may also be useful in designing low vision aids. For example, electronic interfaces such as closed-circuit television have considerable potential for modifying images to compensate for visual losses specific to a given retinal locus and/or layer. 40 To take advantage of this, optimal size, brightness, selective enhancement of contrasts, or border characteristics need to be defined for various types of visual deficit.

Mechanisms should be established to involve visually impaired consumers in the development of products designed to serve their needs. Special panels of visually impaired consumers could be useful in designing and evaluating new prototype devices, and identifying needs that are not being met by devices that are currently available. Many optical aids are rejected by persons with low vision because of inappropriate design. Not only should opinions from consumers be sought; observational studies of visually impaired persons using the aids in a variety of environments are needed to determine how well the aids meet their intended goals.

The development of simple, less costly devices is especially encouraged. Interchangeable components and/or modular devices may make it possible to develop and manufacture devices that would serve large numbers of the visually impaired population.

Special contact lenses and other optical aids need to be developed and evaluated for patients with highly irregular corneas or other severe optical distortions. Substantial numbers of patients with these special needs exist, including those with keratoconus; peripheral corneal dystrophies; keratoglobus; Fuchs' dystrophy prior to surgery; dry eye syndromes of varying severity; distorted, multiple iris apertures; displaced or missing irises; albinism; corneal transplants and refractive surgery; and incipient cataracts in whom cataract surgery is not indicated. Infants born with irregularities or opacities of the ocular media also require special attention. These patients often are not seen in low vision clinics, yet they need detailed and expert care. ⁵⁷

There is a need to develop and evaluate different strategies for training people to improve the utilization of residual vision capacities of the paracentral or peripheral retina; for example, training individuals having central field loss as a result of involutional macular degenerations. Similarly, strategies need to be developed for optimizing function in persons with constricted or hemianopic fields. ⁵⁸ Optimal scanning, peripheral awareness, and space sense skills for effective and safe mobility and orientation must be defined and suitable training methods devised for affected individuals.

The oculomotor behavior of persons with deficits affecting only part of the visual field needs to be studied to identify eye movement strategies and adaptations that may help overcome the handicaps created by visual loss. Training of oculomotor behavior, perhaps using biofeedback techniques, should be explored.

Research is needed on the basic skills and senses related to mobility and orientation. The contributions to mobility of the various attributes of vision need to be identified. ⁵⁹ No accepted method exists for evaluating and grading orientation and mobility performance, but there appears to be considerable potential for developing standard testing procedures ⁶⁰ for quantitatively or qualitatively grading these skills in both partially sighted and nonsighted individuals. The development of such methods would facilitate and encourage correlations of visual function with other senses and skills.

Enhanced "human engineering" studies are needed to aid partially sighted, legally blind, and nonsighted persons. Appropriate coding for guidance purposes, for example through the use of wall colors and/or textured surfaces, floor color and textures, and special lighting, can enhance visual and nonvisual cues to aid function and mobility; all these should be investigated. One possibility is to

use special floor-tile textures to guide individuals to specific locations. The design and development of auditory signals, voice or simulated voice commands, and feedback systems in elevators, traffic signals, and a variety of everyday devices should be encouraged. The development of appropriate simulated environments would be valuable in studies to aid the rehabilitation of the visually impaired patient.

Special support should be considered for studies of visual impairment and blindness in the young and the elderly. In addition, data on the development of many visual functions in infants and young children and on the effects of normal aging on these same factors are needed. Such information would provide baseline data for comparing and evaluating the performance of individuals with visual anomalies.

It is important to characterize the behavior, adaptation, and personal growth of individuals who lose their vision in the first months and years of life. Little is known about the effects of visual experience at various ages prior to sight loss and how this influences the visually impaired person's ability to function. This should be determined.

Visual impairment needs to be detected at the earliest possible age if remedial therapy is to be most effective in preventing further visual loss. Adequate screening tests and therapies for specific forms of visual anomaly are needed.

The nature and the magnitude of the problems created by low vision cannot be assessed by simply measuring the visual loss clinically or even by measuring efficiency in performing visual tasks. A broader view that would consider the entire range of primary and secondary restrictions and disadvantages of visual handicap must be taken to understand and provide for the proper rehabilitation of visually handicapped clients. Furthermore, the impact of an individual's visual impairment on others and society should be studied.

Studies are needed of the attributes of visually handicapped persons who are considered "successful" in life, using a variety of indicators. Factors such as personality, opportunities, training, motivation, certain physical or sensory attributes, and intelligence, need to be assessed to identify those elements, or combinations of elements, that help visually impaired individuals to cope successfully with the world. The results of these studies could lead to new emphases or approaches in visual rehabilitation.

The economic impact of visual impairment needs to be assessed. For this, it is necessary to distinguish among the different subgroups of the visual impairment population, the most obvious distinction being the age of onset. Different considerations are required for those who are born visually handicapped and those who acquire their handicap. The direct costs of rehabilitative services encompass education

for visually handicapped children; job training or retraining; daily living skills; mobility skills; family, vocational, and genetic counseling; home help; transport assistance; special library services; and the special benefits and privileges available to some groups of visually handicapped people. Indirect costs include the cost of a trained employee being obliged to withdraw from his or her job, older persons being obliged to live in nursing homes because of visual loss, or some persons temporarily or permanently withdrawing from the workforce to provide care for a visually handicapped relative or friend. Furthermore, there are costs associated with limited income potential and with loss of tax revenue, both from providing direct benefits to visually handicapped people and from reduced income. And finally, in a modern society the profound noneconomic, personal costs of visual impairment cannot be overlooked.

The effects of technological changes on visually impaired or blind people need to be studied. Many technological advancements make tasks easier for the handicapped, but such changes often are not designed with visually impaired people in mind and sometimes create new limitations for them. For example, many electronic developments have been of substantial benefit to visually handicapped people. Synthesized speech and recordings are being used in calculators; in systems for indicating destinations in trains or elevators; and in instruments such as thermometers, scales, computer terminals, or reading machines. Digital press-button control panels and dialing systems are generally relatively easy for visually impaired persons to use. However, many new automatic procedures, such as banking transactions and ticket purchasing, require visual reading of instructions or messages. Such devices have no human operator from whom assistance can be requested verbally; consequently, visually handicapped persons become relatively disadvantaged. The beneficial and detrimental effects of technological change need to be identified with a view toward rectifying some of the difficulties that have been created. A greater public awareness of the needs of those with visual impairments must be developed to aid their participation in the activities of society.

Implementation Strategy

There is a broad-based need for enhanced development of research to solve the many and varied problems associated with visual impairment and its rehabilitation. Low vision research and special training programs should continue to have high priority for the National Eye Institute, and efforts should be made to attract more proposals for research grants in this field. There is clearly a substantial need to develop additional research

manpower to conduct such investigations. Training programs should be encouraged in institutions where there are sufficient research, clinical, and developmental activities and a diversity of interests. Able young investigators need to be attracted into the field; this might be accomplished by suitable use of the NEI's New Investigator Research Award.

Support should be given to developing a modest number of multidisciplinary centers for research on clinical and rehabilitation services for the visually handicapped. These centers would provide the focus for research and training in visual impairment and include low vision clinics as a major integral component. Such centers would need to have substantial concentrations of low vision patients with both common and uncommon forms of visual loss to develop self-sustaining, meaningful research programs, for training investigators, and for improving multidisciplinary care and rehabilitation programs.

Such multidisciplinary centers for clinical research and rehabilitation services would encourage constructive interaction among investigators from several disciplines. These interactions should foster research that would better serve the broad scope of needs of the visually impaired population and should also ensure that researchers and service providers become better informed of current advances in all aspects of rehabilitative care. The proposed centers, as foci of activity, could provide a variety of research and services that are not currently available.

Centers already exist for other handicaps or in other countries that might serve as models for such low vision centers. Examples are the Central Institute for the Deaf in St. Louis, which is a major educational center that also serves as a research and training resource for those with speech and hearing deficiencies, and the Kooyong Center of the Association for the Blind in Melbourne, Australia, which combines clinical, social, and community services for visually impaired clients.

In general, better means of knowledge transfer are needed among those involved in low vision research. This would help to identify issues that should be investigated across the range of topics related to the care and rehabilitation of partially sighted persons. Sponsorship of a news publication might be the most direct means of facilitating the flow of knowledge in the fields related to low vision, but the publication of abstracts from the literature on vision sciences, ophthalmology, optometry, orientation and mobility, special education, rehabilitation engineering, social work, and psychology would be useful.

Effective coordination is needed for research affecting the multihandicapped. Because research on multiple handicaps often cuts across categorical institutes and agencies, interagency programs are

required to address effectively such problems. Coordinated efforts would optimize research productivity and help people learn to make the best use of their residual capabilities.

There is a need for a standing committee at the national level to coordinate low vision research activities. This interagency committee should include representatives of the various governmental and private agencies that fund research in low vision and rehabilitation, as well as distinguished scientists, service providers, and representatives of the visually handicapped population. Such a committee could identify areas in which jointly sponsored research is desirable, minimize duplication of effort, and identify research areas that are being overlooked because they do not now clearly come under the responsibility of one particular agency. This committee would have the responsibility to identify research and training needs and devise cooperative procedures for fostering, reviewing, and funding research. Also, it would provide a consortium to coordinate activities, such as the development of centers and the organization of meetings.

RECOMMENDATIONS

Based on the foregoing assessment of recent accomplishments, current activities, and research needs and opportunities in Visual Impairment and Its Rehabilitation, the Panel has made the following recommendations concerning research in this field over the next five years. These include areas of ongoing research in which new knowledge and techniques offer particular opportunities for scientific progress, or promising new areas of research in which there is little or no support at present but where there is both great need and high potential for success. Such areas are judged to warrant significantly increased support by the National Eye Institute and other agencies which support such research over the next five years, provided that high quality applications for research grants in these areas are forthcoming.

Research Priorities

- Study the visual characteristics of individuals with specific types of visual impairment.
- Conduct research on the optical, electronic, and other rehabilitative requirements to enhance the capabilities of visually impaired persons.
- Conduct research on basic skills relating to mobility and orientation.

- Encourage "human engineering" studies that will help people with specific visual impairments to interact more independently with their environment.
- Conduct epidemiologic studies of the types and extent of visual impairment resulting from a variety of disorders.
- Develop special contact lenses and other optical aids for patients with corneal or lens problems.
- Study the effects of prior visual experience on the nature and extent of visual impairment and of the ability of people to cope with their impair-
- Study special problems or adaptations required in response to visual impairment in the older population.

RESOURCE REQUIREMENTS

The following table presents a summary of the Panel's estimates of the number of NEI grants necessary to carry out its recommendations for Visual Impairment and Its Rehabilitation in FY 1983. The actual number and cost of grants funded in each subprogram in FY 1981 (the base year of the Plan) are shown in the first column. The second column indicates the number of additional (or fewer) grants the Panel believes should be funded in each subprogram through the end of FY 1983, based on an analysis of current research and of future needs and opportunities. The total number of grants for FY 1983 for each subprogram indicated in the third column is the estimated sum of new and continuing awards to be made in that year along with an estimate of their cost.

The actual number of grants funded in these areas in FY 1983 may of course be either more or less than these projections indicate, depending on the quality, kind, number, and costs of the grant applications NEI receives and the actual availability of funds. Concerning funding, it must be emphasized that the Panel's dollar estimates for FY 1983 do not necessarily indicate what the actual National Eye Institute extramural research budget will be for that vear. However, because the Panel's estimates are based upon detailed documentation of projected research needs and costs, it is hoped that those in the Executive and Legislative branches of the Government who make the final decisions concerning the NEI budget will use them in making informed judgments about the resources required for the support of vision research. In making these estimates the Panel took into account the following factors for each category of research considered:

- Degree of relevance to the research goals specified earlier in this report
- Current level of support by NEI and other organizations
- Recent research accomplishments
- Potential for future development
- Availability of trained manpower
- Likelihood of significant progress over the next three to five years.

The Panel recognizes that in addition to scientific judgments, social, economic, and political considerations will shape the final NEI budget for each year. Therefore, no attempt has been made in this report to make detailed resource estimates beyond FY 1983, although the Council has projected an overall budget for the NEI through 1985 (Volume One). The Panel understands that in the future the Council, with the assistance of scientists knowledgeable in areas of research supported by the NEI, will provide more detailed estimates for the remaining years of the Plan based on actual budgetary experience and ongoing analyses of research progress. In this way the Plan will be modified as necessary on a year-to-year basis.

SUMMARY RESOURCE TABLE

(Dollars in Thousands)

	FY 81		Panel Recommendation FY 83		
Subprograms		Grants* Cost	Add. Grants Cost	Total Grants Cost**	
1. Visual Impairment	2 \$34	(50%)			
2. Rehabilitation	\$132	(50%)			
Total	4 \$166	(100%)	23 \$2,378	27 \$2,794	

^{*} Includes R01, R10, R23, P50, K04, and K07 mechanisms.

^{**} Estimated average cost of grants in FY 1983 is \$103,000.

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